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ABSTRACT

This booklet provides information to families with young children who are deaf or hard of hearing to assist them with communication, socialization, and education choices. It provides: (1) a description of each of the various modes of communication available for use with and among children with are deaf or hard of hearing, including American Sign Language, auditory-verbal, cued speech, manually coded English, and oral communication; (2) a look at various important issues that parents must consider when making communication and education decisions for their child, including audiological considerations, socialization issues, and educational issues; (3) an overview of various educational options, including parent/infant programs, self-contained residential or day programs, bilingual-bicultural programs, cued speech, oral programs, total communication, and mainstreaming; (4) information on basic legal rights and how these rights empower parents to be their child's most effective advocates within the educational system; and (5) a listing of resources to which parents might turn for more information, including publications, organizations, and information sites on the Internet. (CR)

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ED 432 098

OPEN DOORS:

OPTIONS IN COMMUNICATION AND EDUCATION FOR CHILDREN WHO ARE DEAF OR HARD OF HEARING

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First Printing: August 1998

INTRODUCTION

The objective of this booklet is to provide unbiased information to families with young children who are deaf or hard of hearing to assist them with communication, socialization and education choices. The booklet will provide:

- A description of each of the various modes of communication available for use with and among children who are deaf or hard of hearing;
- A look at various important issues that parents must consider when making communication and education decisions for their child;
- An overview of various educational options;
- Information on basic legal rights and how these rights empower parents to be their child's most effective advocates within the educational system; and
- A listing of resources to which parents might turn for more information, including publications, organizations, and information sites on the internet.

COMMUNICATION MODES

This booklet addresses the five modes of communication most widely used in this country. In alphabetical order they are: American Sign Language, Auditory-Verbal, Cued Speech, Manually Coded English, and Oral. Each mode is defined in terms most commonly used by those who advocate for it.

American Sign Language

American Sign Language (ASL) is a visual/gestural language used by many members of the Deaf community in the United States and Canada. It is estimated to be the third or fourth most commonly used language in the U. S. Although it is a language that utilizes the visual/ gestural medium, it is not merely gesture or mime: one cannot understand it until one learns it. For those who wish to learn it as a second language, it takes many years of study and interaction with people who use it. (Summarized from, "A Basic Course in American Sign Language," Humphries, Padden, O'Rourke, 1994.)

ASL is a language in its own right. It is not derived from English. ASL has its own grammar and syntax (patterns of arrangement of words and phrases to make sentences) which are distinct from those of English. For example, plurals and tenses are indicated differently in English and ASL. Other important aspects of ASL are the use of appropriate facial expressions and body movements. Also, fingerspelling is used in instances where there is no sign available; for example, for many proper names and technical terms.

As a primary mode of communication, ASL is most often used in families where the parents are deaf and their native language is ASL. When the young deaf child is fluent in ASL, he or she may then be taught English as a second language so as to facilitate literacy. English may be taught via fingerspelling and/or written format or, by a native speaker of English, via Cued Speech.

If hearing parents wish to learn ASL for use with their deaf child as a primary or secondary language, classes may be available through their public school special education association, a local college, or a community service organization. For proficiency to develop, the parents will need to provide opportunities for the child, and perhaps the whole family, to have contact with and communicate with others in the Deaf Community. There may even be an organization in the area that can provide the family with a tutor or mentor who is deaf. When it comes time to make decisions regarding educational placement, the parents may request that their child be enrolled in a specialized program for the deaf or hard of hearing in which there are other children enrolled who are native ASL users. Keep in mind that frequent and prolonged exposure is required in order for language fluency to develop.

Auditory-Verbal

The auditory-verbal philosophy is that it is the right of children with all degrees of hearing loss to have the option of developing their abilities to listen and communicate using spoken language while growing up in the regular living and learning environments of their communities. Following auditory-verbal principles helps children who are deaf or hard of hearing learn to use their amplified residual hearing and/or a cochlear implant to listen, to process verbal language, and to speak.

The auditory-verbal approach is facilitated by identification of the hearing impairment as early as possible. The child is promptly fitted with appropriate amplification, making use of the most advanced

technology. Audiological management is ongoing to ensure that maximal use of residual hearing is being made through either hearing aids or cochlear implant and any other assistive technology.

Parents and caregivers, as the child's primary language models, are participants in therapy sessions. They are provided with extensive counseling, education, and support so that they will facilitate their child's integration of listening into the development of spoken language. Through individualized therapy sessions with a qualified auditory-verbal therapist, the child is taught to learn verbal language through an emphasis on listening. The child is also taught to monitor his or her own voice and the voices of others to enhance the intelligibility of his or her spoken language. The normal developmental patterns of listening, language, speech, and cognition are followed to stimulate natural communication.

The auditory-verbal approach utilizes diagnostic therapy to continually assess the child's progress over time in each of the above developmental areas. Modifications are made to the child's program when indicated. Support services are also provided to facilitate his or her educational and social inclusion in regular education classes.

The auditory-verbal approach has much in common with the oral approach. Key differences are that with the auditory-verbal method, speechreading is not emphasized. Although the child is not prevented from looking at the person speaking, the child learns to listen first and is not required to look at the speaker's mouth for information. Also, with the auditory-verbal approach, the child is educationally mainstreamed from the start in preschool. In the oral approach, the child is often enrolled in an oral deaf/hard-of-hearing special education program until the child has met the program's criteria for mainstreaming.

Cued Speech

Cued Speech is a visual communication system which, in English, uses eight handshapes -- representing consonant sounds -- in four different locations near the mouth -- representing vowel sounds. Consonants are "cued" in the appropriate vowel locations allowing the cues to be synchronized with what is actually being spoken -- syllable by syllable.

Spoken English cannot be learned through speechreading alone because too many sounds are indistinguishable on the mouth. Using Cued Speech supplements what is seen on the mouth in such a way as to make spoken language clear through vision alone. The system is depicted in its entirety in the following diagrams.

CUED SPEECH CONSONANT HANDSHAPES

1

p
d
zh

2

k
z
v
tH (the)

3

s
h
r

4

n
b
hw (why)

5

m
f
t

6

sh
l
w

7

j
g (go)
th (thumb)

8

y
ng
ch

CUED SPEECH VOWEL PLACEMENTS

MOUTH	CHIN	THROAT	SIDE*
ee (see)	ue (blue)	i (sit)	oe (home)
ur (her)	aw (saw)	a (cat)	ah (father)
	e (net)	oo (book)	u (but)

* /oe/ and /ah/ require slight forward motion; /u/ requires slight downward motion

DIPHTHONGS

SIDE-THROAT	CHIN-THROAT
ie (tie)	ae (cake)
ou (cow)	oi (boy)

Literacy is the original and primary goal of Cued Speech. Cued Speech allows the child who is deaf to "see-hear" the English language as it is spoken -- and to pick it up naturally, in essentially the same way as a child who is hearing. Children who use Cued Speech generally attain language and reading levels equal to those of children who are hearing. This is in stark contrast to the low reading levels attained by the average deaf child.

A significant benefit for the more than 90% of children who are deaf who have parents who are hearing, is that Cued Speech allows these parents to communicate with their children in their own native spoken language. "Most hearing parents can learn the system in a week or two and can become quite proficient in a few months of use," reports Dr. R. Orin Cornett, who has been helping families and professionals all over the world to learn Cued Speech since he invented the system in 1966. This allows for easy and complete communication within the family, throughout childhood, adolescence and into adulthood.

In addition, Cued Speech helps children who are deaf to become better speechreaders and assists with development of auditory discrimination abilities. It has been used successfully with children who have auditory processing disorders, articulation disorders, pronunciation difficulties, and autism. Cued Speech also makes it possible for children who are deaf or hard of hearing to learn foreign languages. It has been adapted to more than 50 foreign languages.

For children whose parents are deaf and whose native language is American Sign Language, Cued Speech can be used at school by teachers whose native language is English so as to facilitate the child's acquisition of English at school.

Although speech is not *required* of the child who uses Cued Speech, many *do* develop speech. If speech is to be a goal for the child, the use of Cued Speech must be supplemented by adequate and coordinated training in audition and speech production.

For more information on Cued Speech parents should contact the National Cued Speech Association. Also, "The Cued Speech Resource Book", by Cornett & Daisey , provides a wealth of information on the subject. (See RESOURCES section for complete references.)

Manually Coded English

These are actually a group of systems, developed for educational purposes, that use signs, fingerspelling, or gestures separately or in combinations to represent English manually. "These systems are not distinct languages as ASL is. Instead, the signs for words are presented in the same order as in English, and invented signs are used in some systems to convey tenses, plurals, possessives, and other syntactical aspects of English. The conceptual base of ASL, however, is maintained in most of these sign systems." ("Choices in Deafness", Sue Schwartz, 1996.) The most common of these systems are Signed English, Seeing Essential English (SEE I), Signing Exact English (SEE II), and Contact Signing/Pidgin Signed English (PSE).

Parents who wish to learn more about Manually Coded English systems should contact their local public school special education associations. Often, the sign language classes provided through the public school systems utilize one of these sign systems rather than ASL.

Oral

The oral approach combines the use of speech, residual hearing, and speechreading as the primary means of communication for persons who are deaf.

The oral communication approach is based on the premise that most children actually have functional residual hearing, and that the speech signal is redundant, so that not every sound must be heard in order to understand a message. For oral language learning to be successful with children who are deaf or hard of hearing, the hearing loss must be identified at an early age, preferably through infant hearing screening procedures before the infant is discharged from the hospital. Amplification would be fitted shortly after the loss is identified, and programs of early intervention must take place during the critical years of language learning (0-6 years), but the sooner the better.

Almost all auditory oral approaches today rely heavily on the training of residual hearing. The traditional auditory/oral approach trains the child with a hearing disorder to acquire language through the use of residual hearing augmented by speechreading (lipreading). In addition, heavy emphasis is placed on amplification devices, such as hearing aids, cochlear implants and assistive devices.

DECISION-MAKING GUIDELINES

Parents ultimately must decide how to communicate with their child who is deaf or hard of hearing and how he/she will communicate with the rest of the world -- deaf and hearing. There are many factors that parents must consider when making these important decisions. This booklet will describe some of them. But please keep the following in mind:

- As time goes by and more is learned about the child's and the family's needs, parents may want to make adjustments to the initially chosen communication strategy.

- Some communication modes are quite compatible with others and can be used in combination in order to meet all of the child's needs, for example:

  For a child who has sufficient aided hearing and whose parents are hearing, auditory-verbal or oral techniques might be used by a qualified therapist or teacher to develop listening, verbal language, and speech skills. If the auditory-verbal or oral method is felt to be insufficient for learning language, then Cued Speech could be used at home to give complete visual access to what is being spoken in the family's native language. At school, although the majority of the curriculum might be presented orally or in English with Cued Speech, the child -- along with other deaf peers -- might also receive formal instruction in ASL by a native ASL signer. A customized approach such as this would assist the child in becoming truly bilingual -- and able to communicate easily with deaf and hearing people.

  For a child who has parents who are deaf, ASL may be used at home as the first language. Parents may begin to teach the child English, as a second language, at home via fingerspelled or written format. Once the child is of preschool age, teachers who are native English speakers might add in the use of Cued Speech to allow for more rapid acquisition of English, so as to facilitate literacy. Of course, just as in the case above, appropriate speech and auditory training could be provided by a qualified auditory-verbal or oral therapist, if the child has a sufficient amount of aided hearing and speech is a goal.

  The various strategies available to parents can be thought of as a "tool kit", where the parents' job is to determine ***which*** tools should be used ***when*** and by ***whom***.

- Unfortunately, many people do not have all of the facts about the available communication modes and educational options for children who are deaf or hard of hearing. Some will even have biases toward one method or another that will color the recommendations they make. Parents should always go to an ***authoritative source*** for information about any of the alternatives being considered. The "Resources" section of this booklet can be helpful in this regard.

Native Language of the Home

The native language of the home is an important factor in making communication choices. Parents who are deaf might favor using ASL with their deaf child, if that is the language of the home. Parents who are hearing might favor a method that allows them to communicate in the spoken language(s) already used in the home.

Audiological Considerations

The amount and quality of residual hearing that a child has after being optimally aided (to the degree that the parents have decided to use the various available technologies), will necessarily have an impact on what type of communication mode the family will be able to successfully use with the child.

Underlying Audiological Principles

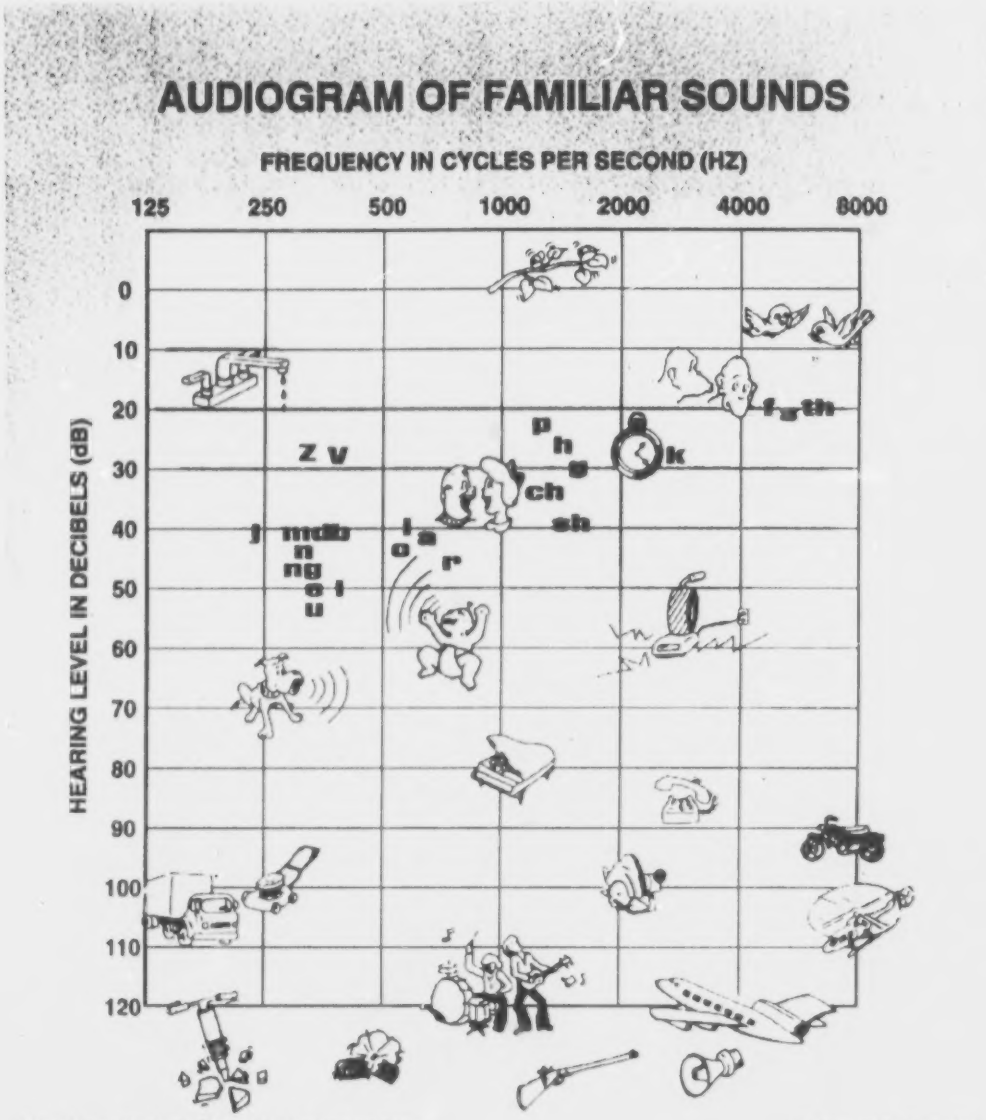
A child's hearing status can be graphically displayed as an "audiogram". There are two dimensions to sound that can be depicted on an audiogram:

(1)Frequency -- low vs. high, roughly analogous to the bass and treble of a piano keyboard, usually expressed in Hertz (Hz) and

(2) Intensity -- the strength of a sound, relative to a starting point and expressed in decibels (dB).

Intensity is displayed vertically and frequency is displayed horizontally. The range of frequencies audible to humans runs from about 20 Hz to about 20,000 Hz but the common audiogram only covers the range from 125 to 8000 Hz. The most important frequencies for the understanding of speech are from 300 to 3000 Hz and are commonly known as the "Speech Frequencies".

In the "Audiogram of Familiar Sounds", pictured below, the Speech Frequencies fall within the shaded, banana-shaped area. In practical terms, this means that, *assuming normal speech effort from six feet away*, all of the sounds of speech fall within the range of loudness and pitch represented by the shaded area. A number of common environmental sounds are also superimposed upon the diagram, illustrating the loudness and pitch at which these sounds normally reach the ear.



Adapted from "Hearing in Children" by Northern and Downs. Williams and Wilkins 1991

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The frequencies for hearing the voice ***without*** understanding speech are from 80 to 300 Hz. Thus someone who hears only low frequencies can turn to a voice, or perceive anger or comfort in a voice without good understanding of the speech superimposed upon the voice -- because they do not have important information carried by the higher frequencies (such as many consonant sounds).

Interpreting the Audiogram

The descriptions contained here describe the performance of someone without hearing aids who is being spoken to in a normal speaking voice from 6 feet away with his or her back turned and getting no visual cues. Note that for most losses between 25 and 95 dB, certain types of hearing aids will provide enough usable hearing to permit an excellent prognosis for speech and language acquisition for children who would ordinarily have learned to hear and speak if they did not have a hearing loss. For some children with greater losses, cochlear implants may accomplish the same.

0-20 dB HL ... no real loss in communication. An older child of 15-18 months should understand directions with back turned, and respond to environmental sounds (e.g. telephone ringing, door knock, toy noises) appropriately. In 8-month-old children, a quiet whisper behind the back should lead to turning and proper localization of the speaker.

25-50dB HL is often described as a mild-to-moderate loss. At six feet away, when the loss is at 50 dB, normal speech levels are unclear without lipreading, and a raised voice is almost always necessary. There is proportionately less of a problem as the loss decreases to 25 dB. The loss is mild enough to be overcome easily if you talk right into the child's ear which is why it is hard to diagnose by casual clinical observation. Nevertheless this type of loss can lead to speech and language delays that have serious educational and communication consequences.

Prognosis for normal speech and language development is excellent with early identification and use of advanced sound-processing hearing aids. These are ideal children for auditory verbal management unless they actually have auditory neuropathies (meaning that they cannot *consistently* process auditory input; see next paragraph) in which case visual approaches such as Cued Speech and/or ASL are by far the management methods of choice. A diagnosis of auditory neuropathy would also impact the type of auditory management the child receives. For example, the child might be fitted with an FM

wireless system to help focus him/her on one source of input, but would not be a candidate for traditional hearing aids or a cochlear implant.

There are a surprising number of children who have auditory neuropathies whose audiograms indicate lots of residual pure tone sensitivity, but whose ABRs (auditory brainstem responses) and middle ear reflexes are absent and who have normal otoacoustic emissions. Explanations of the technical terms used above are beyond the scope of this booklet. However, the terms are presented so that parents can effectively present this issue to their child's audiologist. Every child diagnosed as hearing impaired should have at least one test of middle ear function, including reflexes and otoacoustic emissions to rule out auditory neuropathies.

55-80 dB HL is often described as a moderate to severe loss. At 6 feet without hearing aids and/or visual cues, no communication would be possible. Using a raised voice or talking into the child's ear would elicit some response and comprehension. The prognosis for speech and language development and auditory verbal skills is generally very good with advanced sound-processing hearing aids and FM wireless systems or direct input microphones. Special care must be taken with earmold gauge and bore to insure good high frequency transmission. Many consonant sounds are carried in the higher frequencies. Generally speaking, the wider the bore, the better the high frequency performance of behind-the-ear aids.

85-100 dB HL is considered a severe-to-profound loss. Hearing aids and FM wireless systems with considerable power output, but which can still make very faint sounds audible without exceeding 135 dB in the ear canal, will often do a surprisingly good job in supporting hearing, speech and language. It is important to avoid making decisions based purely on the **unaided** audiogram. Once properly aided (or implanted), the child's unique aided hearing status must be taken into consideration in order to decide on an appropriate communication approach. Often, children with this degree of hearing loss need a visual method of acquiring language, or at least some degree of visual input.

No response below 105 dB is considered a profound loss. The child may be a candidate for a cochlear implant, after a suitable try at hearing aids. If a cochlear implant is not an option, it is quite likely that a visual method of acquiring language, such as Cued Speech and/or ASL will be necessary. Even if an implant is being considered as a future treatment option, with this degree of hearing loss, it is

important to provide the child with visual language input until such time as the implant *might* render this unnecessary.

Aided Hearing and Access to Spoken Language

The audiologist should verify that the child's hearing aid is properly fitted by verifying appropriate sound levels at the ear drum. This can easily be done by using established and recognized clinical procedures in which a measurement of the performance of the hearing aid and earmolds in place on the child's ear is done by special equipment.

Once the audiologist has ascertained that the desired sound levels are being achieved at the ear drum, the audiologist will likely perform an evaluation of the child's aided hearing levels. When the child can detect speech-like signals in the 25-40 dB Hearing Level or better with hearing aids or a cochlear implant (i.e.; the child's aided hearing levels fall within the shaded area of the audiogram pictured on p. 10), there may be enough sound so that eavesdropping can take place and a spoken language can be acquired through the ears. Otherwise, visual supplementation, such as Cued Speech, will be necessary to learn a spoken language.

Aided Hearing and Impact on Speech

Whereas a spoken language can be *learned* auditorily OR visually, people *speak*, for the most part, the way they hear. Children with normal hearing can hear, and usually imitate, the speech of others. Children whose aided hearing does not give them sufficient access to the Speech Frequencies are unlikely to hear or spontaneously produce speech clearly. If intelligible speech is to be a goal for these children, speech training from a qualified therapist will be required.

If a child's speech is not intelligible, the child may need to learn a visual method of expression, such as expressive cueing or signing. There may be some children for whom this might be necessary early on, but who may be able to drop the visual mode once their speech skills have improved.

Socialization Issues

If socialization with others in the hearing community is to be a goal for the child, parents must have a long-range plan for the development of skills such as audition, speechreading and speaking.

On the other hand, it is important to recognize that it may be important for the social and emotional well-being of children who are deaf or hard of hearing to also be provided opportunities to play or go to school with other children who are deaf or hard of hearing. In many cases, even if the family is "hearing", the family, as a whole, may feel a need to socialize or interact with other members of the Deaf Community.

How does a *hearing* family find the Deaf community? Depending on the type of school program in which their child is enrolled, families might develop contacts through the school. In addition, "in many areas of the country, there are community service agencies which were set up to provide advocacy, direct services, information services and counseling for the Deaf. They may also function as cultural centers, sponsoring and organizing festivals, art shows, and youth events, among other things." (Humphries, Padden & O'Rourke, 1994) Parents might seek out such agencies in their own communities so as to find out about activities and events in which they might participate.

If participation in the Deaf community is a goal, the child and the child's family would need to learn to sign, preferably in ASL, which is the primary language of the Deaf community. If given the chance, even when very young, the child who is deaf often finds it quite easy to bond with others with whom they have so much in common. And certainly as the child gets older -- especially in the teenage years -- he or she would need to know ASL in order to develop friendships with others who are deaf and whose primary language is ASL. Likewise, parents (and perhaps siblings) of a child who has deaf friends would need to be able to sign in order to communicate effectively with the child's friends and acquaintances and be a part of the child's life into adulthood.

Parents need to be sensitive to *their* child's socialization needs in order to decide if and when it may be appropriate to begin exposure to ASL.

Educational Issues

Whatever mode or modes of communication are chosen, it is important to consider what the impact will be on the child's opportunity for a good education. In order to be prepared for school, a child must be able to communicate in the language that will be used in the school that the child will attend.

Another overriding consideration, however, is *how well the child is prepared to learn to read.* Low reading levels are a widespread problem for people who are deaf. One cannot become proficient at reading a language that has not been accessible during the primary language-learning years. It is important that parents make sure that whatever mode(s) of communication they choose for their child, that English is being acquired at a rate that will allow the child to become an age-appropriate reader by the early elementary school years.

Geographical Considerations

When making choices for their children, parents should give due consideration to what programs and services are available within reasonable distance of their homes. However, if parents feel there is something that their child needs that is not available in the area, there may be ways to help make it available. Parents should feel free to contact the organizations listed in the RESOURCES section at the end of this booklet for information and guidance on how to obtain the desired programs and services for their child.

Special Characteristics of the Child

Every child, whether they hear normally or not, will have strengths and weaknesses -- and preferences -- with regard to how they learn. Some might naturally be more inclined to learn visually than auditorily and vice versa. The individual child's strengths, weaknesses, and preferences will become more obvious over time. Parents may have to adjust choices initially made for the child.

Also, if the child has learning disabilities or other challenges, in addition to being deaf or hard of hearing, it could affect choice of communication mode. If this is the case, parents should make inquiries with authoritative sources as to which methods of communication and which educational settings have had the most success with other children facing similar challenges.

Time and Effort Required by the Parent

Any method of communication chosen will have to be used consistently and faithfully in order to obtain the desired benefits. Parents must investigate the time that will be required to learn and

effectively use each method and decide whether they are willing and able to make the required commitment.

Actual Experience with the Method over Time

The critical language learning years for a child are from birth to age six. Parents will have to be careful to document their child's progress against pre-set goals -- and be ready to make additions or changes to their "tool kit" as necessary.

Parents should not "give up on" a chosen mode of communication before allowing a suitable amount of time for the child to show the expected progress. On the other hand, parents *should* consider making a change if their child is *not* making the expected progress within the expected timeframe.

EDUCATIONAL OPTIONS

Parent/Infant Programs

Many states provide early intervention services for infants and toddlers from birth to age three. These are commonly referred to as "parent/ infant programs". Under the Individuals with Disabilities Education Act, commonly referred to as "IDEA", states that want to qualify for federal funding of their parent/infant programs must implement a "statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for infants and toddlers with disabilities and their families." (IDEA; PART C; Sec. 633) IDEA requires that an agency be designated within each state to be responsible for early intervention services. That agency must maintain a directory of parent/infant programs available throughout the state. Parents may contact the governor's office within their own state to find out where to obtain this directory.

For a child who is deaf or hard of hearing, early intervention services would include audiological evaluations, speech/language evaluations, provision of assistive technology devices and training in their use, family counseling and training -- especially with regard to the various communication modes, and other related services. All of the services to be provided to an individual family must be formally documented in an Individual Family Service Plan, commonly referred to as an "IFSP".

The "Deaf and Hard-of-Hearing Students Educational Service Guidelines," developed by the National Association of State Directors of Special Education (NASDSE), identify the following ways in which families can benefit from parent/infant programs:

- Immediate and easy access to a professional who can help them understand the hearing loss and its potential effects, both long and short term;
- Immediate and ongoing access to deaf and hard-of-hearing adults and children and their families;
- Immediate and ongoing access to professionals who can help facilitate the development of effective parent-child interaction;
- Immediate and easy access to a professional who can provide information, education and emotional support to families;

- Ongoing access to broad-based information programs that enable families to become more familiar with hearing loss, assessment, sensory devices, communication techniques, management, educational options, and deaf community resources.

Parent/infant professionals should always work in *partnership* with the parents to meet the child's and the family's individual needs. The NASDSE guidelines state that the professionals working with individual families should be "proficient in facilitating family understanding of language and communication options and assisting the family in selecting an appropriate approach for their child....[and in helping the family implement that approach and in actually] using the communication modality and primary language of the child and/or family."

In addition to these publicly provided programs, private speech, language, and hearing therapy may also be available. Parents might wish to seek out and contact a private speech/language/hearing clinic or professional in their area.

Once a child is age three or older, there are various educational options to be considered:

Self-Contained Residential or Day Programs

In self-contained programs, children who are deaf or hard of hearing attend separate special education classes. The teaching staff are certified teachers of the deaf. Professional speech/language therapists are on staff and provide on-site services to the children in accordance with their IEP's (Individualized Education Programs, required by federal law, and further discussed in LEGAL RIGHTS section).

A self-contained program may either be a "residential" program, where children actually live on the school campus, away from their homes; or, it may be a day program, where children commute to the program each day from their own homes.

Self-contained programs can use any one of a number of different communication approaches, sometimes in isolation and sometimes in combination. In this section we will examine some of the more common types of self-contained programs. In alphabetical order they are:

Bilingual-Bicultural (Bi-Bi)

The term "Bilingual-Bicultural" is defined in the NASDSE Guidelines as "being fluent in two languages (ASL and English) and having membership in both deaf and hearing cultures." In a Bi-Bi educational program, ASL is used as the primary language of instruction, with English being taught as a second language through written format. "In addition, the Bi-Bi approach supports instruction in deaf culture, including the history, contributions, values and customs of the deaf community" (Schwartz, 1996).

Advocates of the Bi-Bi approach believe that deaf children need to have access to a completely visual language, such as ASL, during the critical language learning years of 0 - 6. Once a child has become proficient in ASL as a first language, he/she can more easily be taught English as a second language. This is actually the way most deaf children from deaf families learn English -- and advocates of Bi-Bi believe that "deaf children from deaf families who acquire ASL as their first language perform better socially and academically than deaf children from hearing families who did not acquire ASL as their first language" (Schwartz, 1996).

There are a growing number of Bi-bi programs across the U. S. For more information, parents may contact the National Association of the Deaf (see RESOURCES section).

Cued Speech

In a typical self-contained Cued Speech program, the teaching and support staff and all of the children would use Cued Speech as their primary mode of communication. Many other aspects of the program would be quite similar to an Oral program (described on next page), with children receiving specialized, on-site speech, language, and auditory training from qualified professionals.

It is, however, also possible to have Cued Speech integrated into a Bi-Bi or a Total Communication program (described on next page) in order to facilitate the presentation and teaching of English. And, as is the case with a unique program offered at the A. G. Bell Montessori School in Mt. Prospect, Illinois, Cued Speech can be used in a mainstream classroom where hearing and deaf students are educated together and where the teaching staff and all of the students -- hearing and deaf -- use Cued Speech.

For more information on Cued Speech programs available throughout the country, parents may contact the National Cued Speech Association (see RESOURCES section).

Oral

Oral programs fit the general description of self-contained programs, but require staff to have the specialized skills in the areas of teaching the English language and assisting children with development of their speechreading, listening and speaking skills. Once a child is "ready", in terms of his/her language, reading, and oral communication skills, mainstreaming would be sought for the child.

Parents may contact the Alexander Graham Bell Association for the Deaf for more information about existing Oral programs (see RESOURCES section).

Total Communication

NASDSE guidelines define this as "a philosophy of communication which employs a combination of components of oral and manual teaching modes using sign, lipreading, fingerspelling, use of residual hearing, speech, and sometimes Cued Speech." Total Communication programs generally use one of the English Sign Systems, explained above in the Communication Modes section.

In the book, "Choices in Deafness," by Sue Schwartz, she cautions, "Over the years, many school programs have used the total communication label to describe their systems. These systems, however, may differ in the value and emphasis they place on each communication modality."

In order for a parent to know whether their local Total Communication program meets their child's individual needs, parents should get a complete description of the program from the Supervisor. It would be helpful to know the program's objectives, the communication modes in use, and the amount and types of professional services provided to the average child. Parents should also schedule one or more observations of the program. Of course, it is a good idea to investigate any educational program in this manner but, due to the implicit variability in Total Communication programs, it is most essential with this type of program.

Mainstreaming

Mainstreaming is the integration of "students with disabilities...with their non-disabled peers to the maximum extent possible, when appropriate to the needs of the student with a disability" (NASDSE Guidelines, 1994). Federal law requires that disabled children be educated in the "least restrictive environment," which, for deaf children, can be argued to be a self-contained program OR a mainstream program, depending on the needs and abilities of the child. So parents do have important decisions to make in this regard.

Mainstreaming may be a parent's choice from the very beginning or the child may be moved into the mainstream from a self-contained program if mainstreaming is a goal for the child and it is determined that the child is "ready". There must be objective measures for determining whether a child is ready; for example, whether or not the child falls into the range of language and reading levels required for academic functioning at the child's grade level. Children may be mainstreamed for part or all of their school day.

A child who is mainstreamed is entitled under federal law to a number of possible special accommodations. These include interpreters, transliterators, personal FM units, real-time captioning, note takers, etc. The child might also be provided with auxiliary services -- like itinerant services from a teacher of the deaf or therapy from a speech/ language pathologist. Whatever the child *needs* should be clearly stated in the child's Individualized Education Program (IEP). If it is in the IEP, the school *has to* provide it.

Because hearing impairment is usually considered a "low-incidence" handicap, many school districts within a certain geographical area may team together and specify one particular school as a "cluster site" for students who are deaf or hard of hearing. In other respects, these schools are regular education sites, where children who have normal hearing also attend.

At a cluster site, there are self-contained classrooms where students who are deaf or hard of hearing can spend any part or all of their school day. There are also regular education classrooms where the students who are deaf or hard of hearing, who are ready to be mainstreamed for all or part of their day, may attend classes with the students who hear normally.

For the portion of their day that they are mainstreamed, students at cluster sites would be provided with the same types of

accommodations that are afforded to students who are totally mainstreamed. But, since they are at a site which maintains a self-contained program, they would have access to the professional services of teachers of the deaf and speech/language pathologists on a more regular basis than a totally mainstreamed student would.

LEGAL RIGHTS

There are important federal laws that empower the parents of children who are deaf or hard of hearing to advocate effectively for their children within their school system. The three most important laws are the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act (ADA).

Parents are their child's most important advocates. They must educate themselves so as to have a clear understanding of their child's rights under these various laws. Parents can find the actual text of the laws and information regarding interpretations and applications of the laws by visiting their local public libraries or bookstores or by contacting any one of a number of organizations and/or web sites, as indicated in the Resources Section at the end of this booklet.

The Americans with Disabilities Act (ADA)

The Americans with Disabilities Act provides the most general protections of the three laws mentioned above. It prohibits any public entity (which includes public schools) from discriminating against an individual on the basis of a disability.

The wording found in the ADA regulations is very powerful. It prohibits a public entity from providing an "individual with a disability with an aid, benefit, or service that is not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others." Thus, the parents who can demonstrate that their child requires a particular educational placement in order to have the same opportunity to achieve as well in school as his hearing peers, has the weight of this law behind them.

For example, if a child's hearing loss was identified early enough and the family has had effective communication (in their chosen communication mode), the child may have age-appropriate or nearly age-appropriate language skills. The parents may discover that the average language and reading levels of the children in the local self-contained program are significantly below age level and that the curriculum is geared toward a lower level of achievement than that offered in the mainstream. The parents would be justified in requesting a mainstream placement with a sign-language or oral interpreter or Cued Speech transliterator rather than a self-contained placement. Their child should have the same opportunity to achieve as well in

school as other children do.

The ADA also specifically requires a public entity to "take appropriate steps to ensure that communications with [individuals] with disabilities are as effective as communications with others." They must provide appropriate auxiliary aids and services (such as an interpreter or transliterator, an FM system, captioning, etc.) when necessary to afford the child with "an equal opportunity to participate in, and enjoy the benefits of, a service, program, or activity conducted by a public entity". AND, in determining what type of aid or service is provided, the public entity "*must give primary consideration to the requests of the individual with the disability*".

The prohibitions against discrimination by public entities, as described above, are found in Title II of the ADA. Another part of the law, Title III, prohibits private schools from discrimination on the basis of disability. Reasonable accommodations, such as those required for public entities, are also required under Title III, unless providing such accommodations would result in an undue financial burden or a fundamental alteration in the nature of the service being provided.

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act, hereafter referred to as IDEA, protects the rights of children with disabilities to a free appropriate public education. As amended in 1997, the new IDEA places a much greater emphasis on making sure that the methods used to educate these children are effective and provide "full educational opportunity". The amended law clearly states that one of its purposes is to "prepare [children with disabilities] for employment and independent living." (IDEA 1997; PART A; Sec. 601)

A child with a hearing impairment is covered by the provisions of IDEA if, by reason of his or her hearing impairment, he or she needs special education and related services. Related services includes transportation, speech-language pathology, audiology, and other such services as may be required to assist the child in benefiting from special education. Special education is defined as "specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability". (IDEA 1997; PART A; Sec. 602)

In the past, the term "specially designed instruction" was never defined -- and school officials could exclude children who were deaf or hard of hearing from coverage under IDEA as long as they had no

significant developmental delays. Under the new IDEA, specially designed instruction is defined as "adapting the content, methodology, or delivery of instruction to (1) address the unique needs of an eligible child under this part that result from the child's disability, and (2) ensure access of the child to the general curriculum, so that he or she can meet the educational standards within the jurisdiction of the public agency that apply to all children." (IDEA Regulations; Sec. 300.24(b)(3))

This definition seems to support the position that a child who is deaf or hard of hearing may be eligible under IDEA 1997 -- and the public schools must provide appropriate programming for this child -- even if the child is not developmentally delayed, if it can be shown that the child needs specially designed instruction. For example, a child whose primary mode of communication is English with Cued Speech will need a program that provides for delivery of instruction in that mode to ensure access to the general curriculum. The fact that the child may have age-appropriate academic skills does not change the fact that the child needs this specialized instruction to *continue* to make appropriate progress. The child may also need related services, such as speech therapy and auditory training.

Under IDEA, the key to ensuring that the child's right to a free appropriate education are being met is the Individualized Education Program, or "IEP". An IEP must include a statement of the child's present levels of educational performance. It must state measurable annual goals, as well as benchmarks or short-term goals. It must identify ***all special education (as defined above) and related services*** that must be provided for the child to advance appropriately toward attaining the annual goals, to be involved and progress in the general curriculum ... and to participate in extracurricular and other nonacademic activities. It must also specify *all required supplementary aids and services*, including an FM system and perhaps even hearing aids (for use at school, only), if the child does not already have personal hearing aids.

IEP's are developed by an IEP team which generally consists of the child's parents, special and general education teachers, special service providers, and a special education coordinator. IDEA *guarantees* parents the right to be a part of their child's IEP team. Parents also have the right to have an advocate, attorney or other individual with knowledge or special expertise regarding their child accompany them at IEP meetings.

IDEA 1997 requires that the IEP team **"consider the communication needs of the child, and in the case of a child who is deaf or hard of hearing, consider the child's language and communication needs, opportunities for direct communications with peers and professional personnel in the child's language and communication mode, academic level, and full range of needs, including opportunities for direct instruction in the child's language and communication mode."** (IDEA 1997; PART B; Sec. 614.) Parents are their child's most important advocates. Parents need to be aware of this very important legal provision and make sure that all of these needs are addressed in their child's IEP.

For example, if it is determined that a child needs to improve his or her speech and language skills, the IEP should state this and should specify that the child be provided with speech/language therapy, the number of minutes per week that will be provided, and the specific speech and language goals that will be worked on during the period covered by the IEP (usually one school year). If it is agreed that the child needs all instruction presented in a particular language and communication mode (e.g.; ASL, a signed English system, or English -- with or without Cued Speech) and needs direct communication with teachers and peers in that language and communication mode, the IEP should state this and the school must place the child in a program that provides such services.

The IDEA requires that a "continuum of alternative placements" be made available to meet the needs of children who are deaf or hard of hearing. It is *not* acceptable for a school district to refuse to provide a particular placement simply because it is not available. The district is required to inform parents of their right to a continuum of alternative placements and to fill a gap in this continuum, if this is necessary in order to provide an appropriate education for a child. If the district does not fill the gap, the state department of education must do so.

It is very important that parents not only learn what their rights are under the law, but also that they learn and use the right terminology when they make requests to their school systems. For example, parents should always speak of whether or not an educational placement is "appropriate" for their child -- not whether it is "best" for their child. They must speak of whether or not a communication mode is "effective" for their child -- not "better" for their child. Parents must *read* the law and/or books that explain the law in order to advocate effectively for their children.

(The above two paragraphs were summarized from the book, "IDEA Advocacy for Children Who are Deaf or Hard of Hearing: A Question and Answer Book for Parents and Professionals", Singular Press, 1997, by Bonnie Poitras Tucker, J.D.)

Section 504 of the Federal Rehabilitation Act of 1973

Section 504 simply prohibits discrimination against people with disabilities by entities that receive federal aid. Many of the provisions found in the ADA were modeled after Section 504. If a child who is deaf or hard-of-hearing does not qualify for special education under IDEA, the the child would still be covered under Section 504 and would have the right to any necessary related services (e.g., speech therapy, an interpreter or transliterator, an FM system, etc.). Because Section 504 is more specific than the ADA, it may be a better legal tool for parents than the ADA when requesting specific educational services.

Section 504 also is important in that it mandates that every state set up a Protection and Advocacy (P & A) agency that can provide information and advocacy services to all persons with disabilities. Parents should contact the governor's office in their state to find out the name and address of their P & A agency. A list of these agencies is also available from the Children's Rights section of the Alexander Graham Bell Association for the Deaf (see RESOURCES section).

Legal Assistance

In addition to Protection and Advocacy agencies, there are other sources of legal assistance available to parents. These include the Center for Law and the Deaf (based at the National Association of the Deaf), the A. G. Bell Association's Children's Rights Coordinators (see RESOURCES section), and, of course many private practice attorneys and law firms that specialize in disability and/or special education law.

Often, school officials will defer to parents' requests without any need for formal legal proceedings if it is apparent that the parents have done their "homework" and can offer information that shows that the law is on their side. However, in some cases, this may not be enough. Parents may need to retain the services of an attorney or other specially trained advocate. In some cases, these services may be made available without charge.

RESOURCES

Publications

There are many publications available to assist parents in finding more information on the topics covered in this booklet. The following books, listed in alphabetical order, may be a useful starting point for some parents:

- "Auditory-Verbal Therapy for Parents and Professionals"; by Warren Estabrooks; published in 1994 by the Alexander Graham Bell Association for the Deaf.

- "A Basic Course in American Sign Language" (text, study guide and video tape); by Tom Humphries, Carol Padden, and Terrence J. O'Rourke; illustrated by Frank A. Paul; second edition published in 1994 by T. J. Publishers, Inc.

- "Choices in Deafness"; edited by Sue Schwartz; published in 1996 by Woodbine House.

- "The Cued Speech Resource Book for Parents of Deaf Children"; by R. Orin Cornett, Ph.D. and Mary Elsie Daisey, M.Ed.; published in 1992 by the National Cued Speech Association.

- "Deaf in America: Voices from a Culture"; by Carol Padden and Tom Humphries; published in 1988 by Harvard University Press.

- "Educating Deaf Children Bilingually"; by Shawn N. Mahshie.; published in 1995 by Pre-College Publications, Gallaudet University, Washington, D.C.

- "Educational Audiology for the Limited-Hearing Infant and Preschooler"; by Doreen Pollack, Donald Goldberg, and Nancy Caleffe-Schenck; published in 1997 by Charles C. Thomas, Publisher, Ltd.

- "IDEA Advocacy for Children Who are Deaf or Hard of Hearing: A Question and Answer Book for Parents and Professionals"; by Bonnie Poitras Tucker, J.D.; published in 1997 by Singular Press.

- "Parents and Teachers: Partners in Language Development"; by Audrey Ann Simmons-Martin, Ed.D. and Karen Glover Rossi, M.A.; published in 1990 by the Alexander Graham Bell Association for the Deaf.

Some of these -- and many other helpful publications -- may be found through local libraries and bookstores. Parents may request that their local librarian access the inter-library loan system to help with hard-to-find items.

As an alternative, parents may find it more productive to start with a few of the major organizations that serve the deaf and hard-of-hearing communities. Many of these organizations have catalogues which contain lists of publications that may be ordered directly through the organizations. And most offer periodic newsletters or magazines to members. Membership is normally quite reasonable -- and some offer first-year free memberships to parents of newly diagnosed children. See below for a list of such organizations.

Organizations

There are many organizations that have been established over the years to serve people who are deaf or hard of hearing and their families. Some of these organizations tend to promote certain mode(s) of communication over other modes. Parents who contact a variety of these organizations will be more successful in obtaining the wide array of information they need to make decisions that are best for their own individual children.

Many of these organizations sponsor periodic conventions or seminars, which provide valuable opportunities for parents to learn more about a wide variety of topics in categories such as: technology; education; communication; Deaf Culture; legal rights; parenting; etc. These events also provide parents with opportunities to network with other parents, others who are deaf or hard of hearing, and educators and other professionals in deaf-related fields.

Some organizations even sponsor family camps, where a family can attend together and receive training and practice in the use of one or more communication modes. Camps may include formal presentations on variety of relevant topics, panel discussions, social outings, etc. They also provide great socialization and networking opportunities.

Listed below are a few organizations that parents may want to contact. The information presented for each was taken from the annual directory published by the National Institute on Deafness and Other Communication Disorders, National Institutes of Health, entitled: "1998 Directory of Information Resources for Human Communication Disorders". In order to obtain a copy of the complete directory, which

includes listings for over a hundred different organizations, including a brief description of each, you should contact the NIDCD Information Clearinghouse (see listing below).

- **Alexander Graham Bell Association for the Deaf (A. G. Bell)**
  3417 Volta Place, NW, Washington, DC 20007
  Voice/TTY: (202) 337-5220
  FAX: (202)337-8314
  E-mail: AGBELL2@aol.com
  Internet: http://www.agbell.org/

  [For legal information and assistance, parents should contact the A. G. Bell Association and ask for information on how to contact the **Children's Rights Coordinator** for their state.]

- **American Sign Language Teachers Association**
  c/o National Association of the Deaf
  814 Thayer Avenue, Silver Spring, MD 20910-4500
  TTY: 301-587-0628
  Voice: 301-587-1788
  Fax: 301-587-1791
  E-mail: ASLTA@aol.com
  Internet: http://www.nad.org (Press ASLTA)

- **Auditory-Verbal International (AVI)**
  2121 Eisenhower Avenue, Suite 402, Alexandria, VA 22314
  Voice: (703) 739-1049
  TTY: (703) 739-0874
  FAX: (703) 739-0395
  E-mail: AVI@auditory-verbal.org
  Internet: http://www.auditory-verbal.org

- **Center for Law and the Deaf** (based at NAD; see listing for NAD, below)

- **National Association of the Deaf (NAD)**
  814 Thayer Avenue, Silver Spring, MD 20910-4500
  Voice: (301) 587-1788
  TTY: (301) 587-1789
  FAX: (301) 587-1791
  E-mail: NADHQ@juno.com
  Internet: http://www.nad.org

- **National Association of State Directors of Special Education, Inc. (NASDSE)**
  1800 Diagonal Road, Suite 320; Alexandria, VA 22314
  Voice: (703) 519-3800
  Fax: (703) 519-3808

- **National Cued Speech Association (NCSA)**
  c/o Cued Speech Discovery (Information Services/Bookstore)
  23970 Hermitage Road, Cleveland, OH 44122-4008
  Toll-Free Voice/TTY: (800) 459-3529
  E-mail: CuedSpDisc@aol.com
  Internet: http://www.cuedspeech.org

- **National Information Center on Deafness (NICD), Gallaudet University**
  800 Ford Avenue, NE, Washington, DC 20002-3695
  Voice: (202) 651-5051
  TTY: (202) 651-5052
  FAX: (202) 651-5054
  E-mail: nicd@gallux.gallaudet.edu
  Internet: http://www.gallaudet.edu/~nicd

- **National Institute on Deafnesss and Other Communication Disorders (NIDCD) Information Clearinghouse**
  1 Communication Avenue, Bethesda, MD 20892-3456
  Voice: (800) 241-1044
  TTY: (800) 241-1055
  FAX: (301) 907-8830
  E-mail: nidcd@aerie.com
  Internet: http://www.nih.gov/nidcd/clearing.htm

Other Resources

Internet sites which provide information on federal disability law include:

- Office of Special Education and Rehabilitative Services (OSERS) at the Department of Education
  Internet address: http://www.ed.gov/offices/OSERS/IDEA

- Federal Education Administration Online
  Internet address: http://www.lrp.com/ed/

The two organizations that sponsored the development and distribution of this booklet are Oticon and the Academy of Dispensing Audiologists (ADA). Oticon, the oldest manufacturer of hearing devices, offers a complete line of hearing instruments ranging from conventional analog to advanced digital signal processing technology. For the most up-to-date information on hearing instruments and other assistive devices available to help children who are deaf or hard of hearing, and for information on audiological services available in any given area, parents may contact Oticon or the ADA as follows:

- **Oticon, Inc.**
  29 Schoolhouse Road, P. O. Box 6724, Somerset, NJ 08875
  Voice: 732-560-1220
  Fax: 732-560-0029
  Internet: http://www.oticonus.com

- **Academy of Dispensing Audiologists (ADA)**
  3008 Millwood Avenue, Columbia, South Carolina 29205
  Voice: 803-252-5646
  Fax : 803-765-0860
  Internet: http://www.audiologist.org